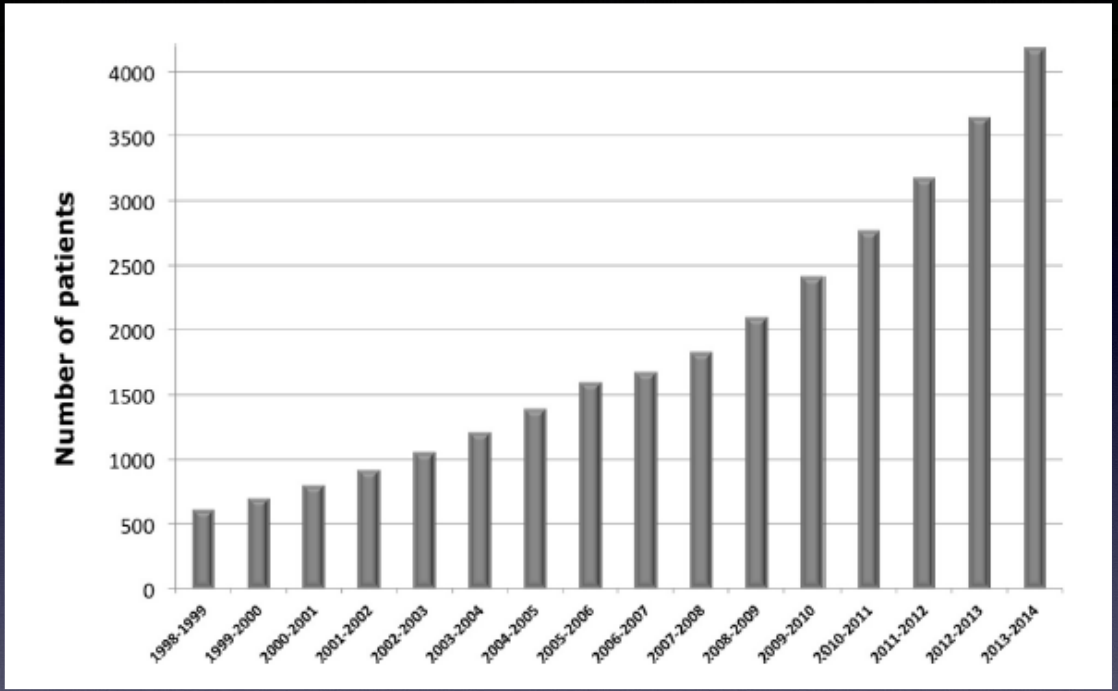
Program Development

Guideline data from overseas

Tim Hornung
Auckland Hospital

Surgery for Congenital Heart Disease

- More than 85% of children with CHD will now survive to adulthood
- Most congenital heart disease is not cured by surgery and has important sequelae
- Ratio of adults : children with CHD is now 2:1
- Most children with “repaired” CHD are well - many important complications only arise in adulthood

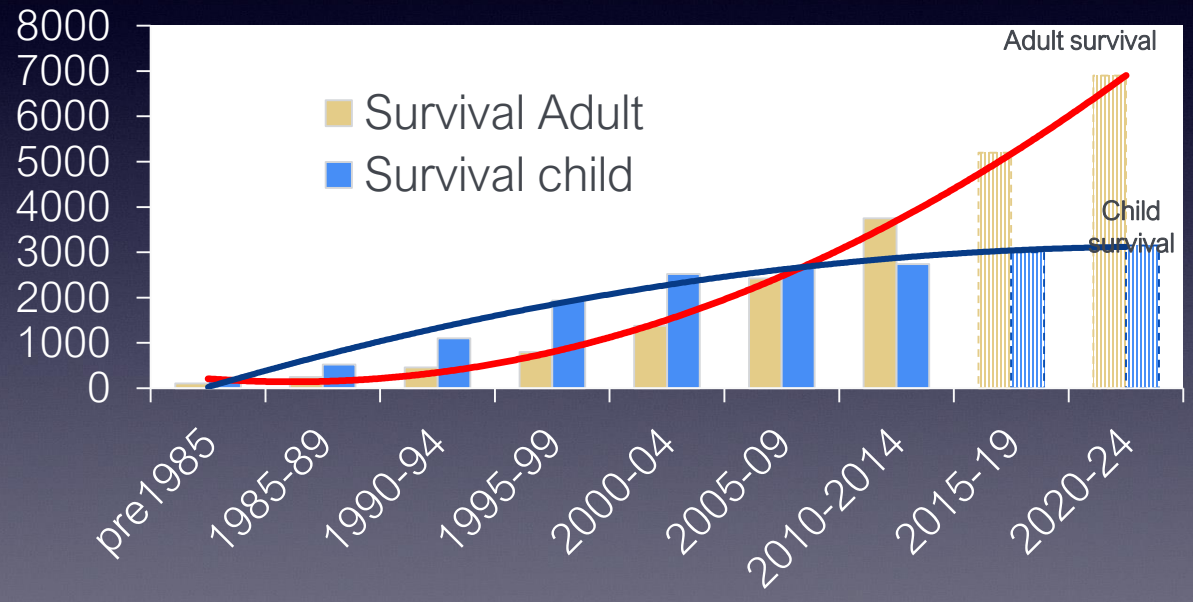


Patients followed at the Montreal Heart Centre 1998 - 2014

Canadian Journal of Cardiology 30 (2014) S410—S419

NZ Congenital Cardiac Surgery

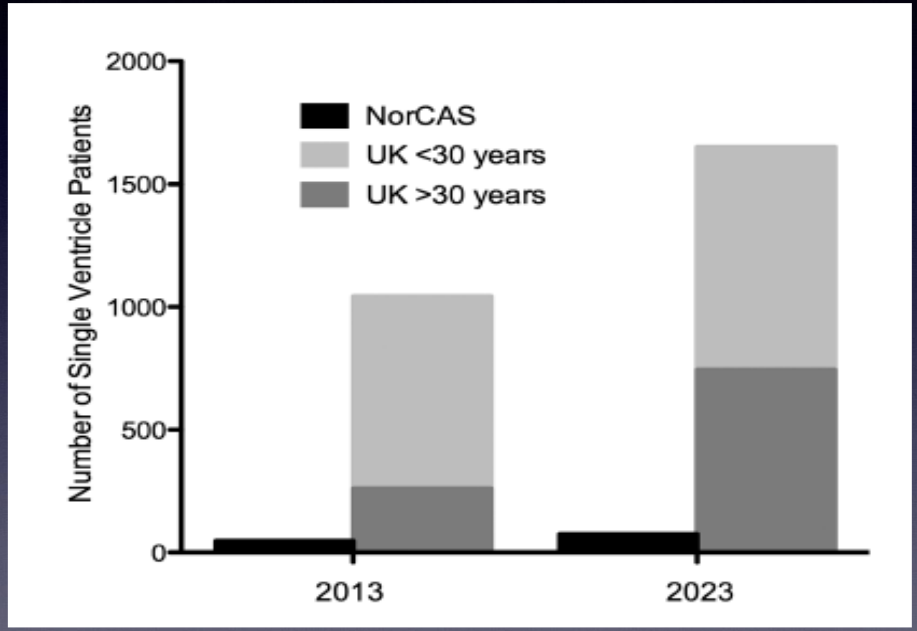
Predicted Future Survival for Child and Adult patients



ACHD: Prevalence

- Quebec: 6.1 / 1000
- Netherlands: 3.2 / 1000
- **N.Z. equivalent: 14,400 – 27,000**
- **Australia equivalent: 77,000 – 146,000**

Single Ventricle Patients



Coats L, *et al*. *Heart* 2014;**100**:1348–1353. doi:10.1136/heartjnl-2013-305336

Establishing Standards

Acceptable staffing levels for different centres

- National or state ACHD surgical centre
- Major non-surgical regional centres
- Smaller centres

Establishing Standards

Acceptable staffing levels for different centres

- Recommended cardiologist FTE
- Nurse specialist / nurse practitioner FTE
- Psychologist FTE

ACC/AHA 2008 Guidelines for the Management of Adults With Congenital Heart Disease

Table 2. Personnel and Services Recommended for Regional ACHD Centers

Type of Service	Personnel/Resources
Cardiologist specializing in ACHD	One or several 24/7
Congenital cardiac surgeon	Two or several 24/7
Nurse/physician assistant/nurse practitioner	One or several
Cardiac anesthesiologist	Several 24/7
Echocardiography*	Two or several 24/7
• Includes TEE, intraoperative TEE	
Diagnostic catheterization*	Yes, 24/7
Noncoronary interventional catheterization*	Yes, 24/7
Electrophysiology/pacing/AICD implantation*	One or several

Planning the specialized care of adult congenital heart disease patients: from numbers to guidelines; an epidemiologic approach.

Ariane J. Marelli, Judith Therrien, Andrew S. Mackie, Raluca Ionescu-Ittu, Louise Pilote Québec,Montreal,Canada

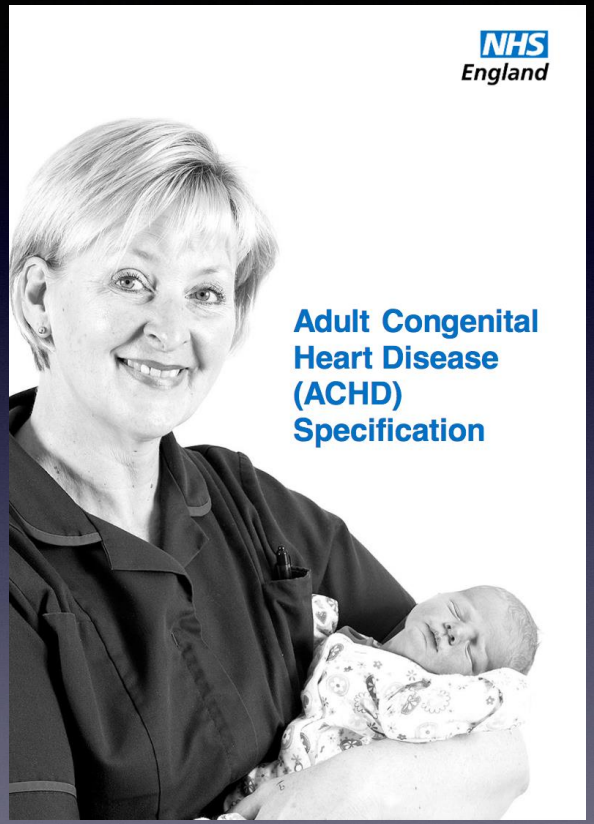
We examined the distribution of disease and health services in pediatric and adult populations and examined the evidence for pressure points during the transition process. Published data on 6 of the largest regional ACHD centers were used to model regional center care. We reviewed determinants and recommendations for follow-up in regional centers. We explore 3 scenarios of referral patterns to regional centers, examining their impact of the number of centers required per country population. In conclusion, we demonstrate that 1 regional ACHD center for a population of 2.0 million adults appears to be closer to what is required for improving access to specialized care for patients with ACHD in the United States and Canada. (Am Heart J 2009;157:1-8.)

Recommendations for organization of care for adults with congenital heart disease in Europe: a position paper of the Working Group on Grown-up Congenital Heart Disease of the European Society of Cardiology

Helmut Baumgartner et al for the Working Group on Grown-up Congenital Heart Disease of the ESC.

Table I Staff requirements of a specialist grown-up congenital heart centre

Adult/paediatric cardiologist with GUCH certification	At least 2
GUCH imaging specialist (echo, CMR, CT)	At least 2
Congenital invasive cardiologist	At least 2
CHD surgeon	At least 2
Anaesthesiologist with CHD experience and expertise	At least 2
Invasive electrophysiologist with GUCH experience	At least 1
Psychologist	At least 1
Social worker	At least 1
Cardiovascular pathologist	At least 1



- UK review of ACHD Services (Draft: 2013, published 2016)
- Chair: John Deanfield

Local ACHD Centre

- The Local ACHD Centre will be staffed by one cardiologist with an interest in ACHD who will be supported by others who visit on an outreach basis from Specialist Surgical Centres or Specialist Cardiology Centres
- The cardiologist with an interest in ACHD would also have a formal liaison role between the ACHD network and the local adult cardiac network
- The cardiologist with an interest in ACHD would be supported by specialist MDT sessions, via video conferencing if geography precludes attendance in person
- 0.25 FTE ACHD specialist senior nurse (with training / in-reach)

Local ACHD Centre

- Delivery of shared care under protocols established within the network
- Ensure the delivery of long term follow-up as appropriate to need
- Understand when to refer the patient to different network settings to meet changing clinical need
- Basic cardiac diagnostic services
- Joint working with palliative care
- Management of low risk pregnancies

ACHD Specialist Cardiology Centre

- Will not perform surgical procedures or catheter interventions.
- A Specialist ACHD Cardiologist (0.8 FTE ACHD) and a cardiologist committed to ACHD (0.5 FTE) would be based there and would also work across the network, including at Local ACHD Centres, according to local circumstances
- 1:4 rota comprising congenital and non-congenital cardiologists
- At least 2 FTE ACHD Specialist Nurses

ACHD Specialist Cardiology Centre

- On-going ACHD patient management
- Broad range of diagnostic services, including non-invasive imaging, delivered at the same quality as those in Specialist Surgical Centres
- Simple electrophysiology work – only if agreed as part of network wide arrangements and following MDT consideration
- On-going management of pacing
- Management of ACHD in pregnancy, contraceptive advice and pre-pregnancy planning, with an understanding of when to refer to Specialist Surgical Centres in high risk cases

ACHD Specialist Surgical Centre

- ACHD network management – pathways and policies will be established at this level, in partnership with constituent organisations in the network, and delivery of consistent services in line with these is overseen by the centre
- Proactively lead training, development and research around ACHD across the network
- All ACHD surgery to be delivered only by trained congenital cardiac surgeons with anaesthetic cover provided by those with appropriate ACHD training
- All ACHD catheter interventions, compliant with BCCA guidelines
- Access to hybrid procedures – combined ACHD surgical / ACHD cardiology working.

ACHD Specialist Surgical Centre

- Complex electrophysiology, complex pacing and ICD procedures
- Invasive and non-invasive imaging
- Transition and transfer clinics
- 24 hour on-call availability, 7 days per week
- In-reach working by cardiologists from the Specialist Cardiology Centre
- Working links to other specialist specialties such as congenital transplantation services, genetics, National Pulmonary Hypertension Service
- Very complex patients requiring non-cardiac surgery to be managed in this setting in order to have access to anaesthetists with ACHD experience
- Joint management of ACHD patients with high risk pregnancy

ACHD Specialist Surgical Centre

- Must deliver 24/7 emergency care and inpatient admission facilities including a minimum rota of Specialist ACHD Cardiologists of 1:4.

- BCCA definition of a Specialist ACHD Cardiologist:
  - If entire practice is within congenital cardiology, spend ≥50% of clinical time in ACHD.
  - If practising in adult cardiology, spend ≥ 75% of clinical time in ACHD

- Be able to demonstrate close links with local ACHD centres
  - Joint clinics or case conference meetings
  - Clear referral pathways

ACHD Specialist Surgical Centre

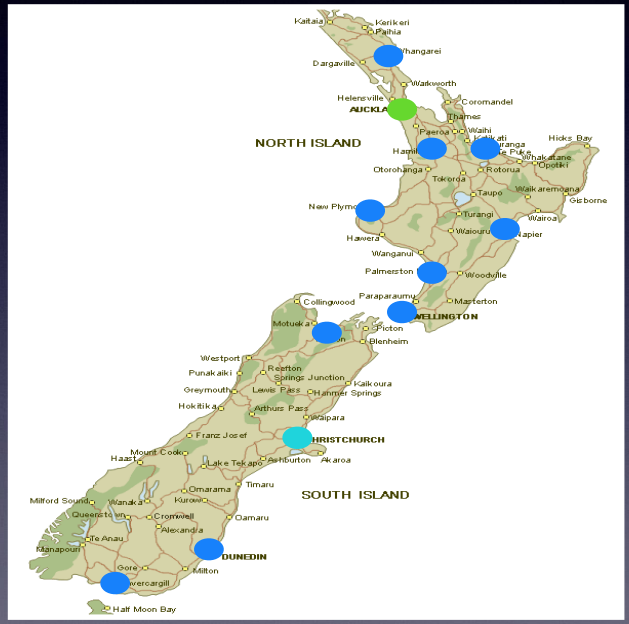
- Each Specialist Surgical Centre must be staffed by a **minimum of 4 FTE specialist ACHD cardiologists** with an indicative maximum patient workload of 1,500 per WTE cardiologist.
- Congenital Cardiac Surgeons who are each the primary operator in a minimum of 125 congenital heart operations per year (in adults and / or children).
- A Consultant Congenital Cardiac Surgeon must not partake in an on-call rota more frequent than 1:4 (requiring a minimum of 4 surgeons).

ACHD Specialist Surgical Centre

- Each Specialist Surgical Centre will employ a minimum of 5 FTE Specialist ACHD Nurses whose role will extend throughout the network.
    - The precise number (above the minimum 5) and location of these nurses will depend on geography, population and the configuration of the network.
- Each Specialist ACHD Surgical Centre will employ a minimum of two WTE psychologists, one of whom will have responsibility for delivering services across the network
- Each Specialist Surgical Centre must have onsite administrative support sufficient to provide continuous daytime cover and to respond to patient enquiries.

NZ ACHD Blueprint

- Single ACHD specialist surgical centre
- ? CHD specialist cardiology centre for the South Island
- ? CHD specialist cardiology centre for the lower North Island
- Local ACHD centres in all cardiology centres



NZ ACHD Blueprint

- Adequate but realistic staffing levels
  - Particular importance of senior nursing staffing
- Commitment to adequate ACHD service provision from DHBs and cardiology departments around the country
- Agreed models for interaction between centres

Regular Activities

- Annual ACHD Scientific meeting
  - Somewhere nice - ? Queenstown